

# SENATE BILL NO. 553

102ND GENERAL ASSEMBLY

INTRODUCED BY SENATOR ESLINGER.

2141S.01H

KRISTINA MARTIN, Secretary

## AN ACT

To amend chapter 191, RSMo, by adding thereto eight new sections relating to the Missouri Parkinson's disease registry.

*Be it enacted by the General Assembly of the State of Missouri, as follows:*

Section A. Chapter 191, RSMo, is amended by adding thereto  
2 eight new sections, to be known as sections 191.1820, 191.1825,  
3 191.1830, 191.1835, 191.1840, 191.1845, 191.1850, and 191.1855,  
4 to read as follows:

191.1820. 1. Sections 191.1820 to 191.1855 shall be  
2 known and may be cited as the "Missouri Parkinson's Disease  
3 Registry Act".

4 2. For purposes of sections 191.1820 to 191.1855, the  
5 following terms mean:

6 (1) "Advisory committee", the Parkinson's disease  
7 registry advisory committee established in section 191.1830  
8 to assist in the development and implementation of the  
9 registry;

10 (2) "Medical university", the University of Missouri  
11 and any other medical research university in the state that  
12 enters into a memorandum of understanding with the  
13 University of Missouri if deemed appropriate by the  
14 University of Missouri;

15 (3) "Parkinson's disease", a chronic and progressive  
16 neurologic disorder that:

17 (a) Results from deficiency of the neurotransmitter  
18 dopamine as the consequence of specific degenerative changes  
19 in the area of the brain called the basal ganglia;

20 (b) Is characterized by tremor at rest, slow  
21 movements, muscle rigidity, stooped posture, and unsteady or  
22 shuffling gait; and

23 (c) Includes motor and nonmotor symptoms and side  
24 effects including, but not limited to, autonomic  
25 dysfunction, thinking and mood changes, and other physical  
26 changes;

27 (4) "Parkinsonism", any condition that causes a  
28 combination of the movement abnormalities observed in  
29 Parkinson's disease, such as tremor at rest, slow movement,  
30 muscle rigidity, impaired speech, or muscle stiffness, with  
31 symptoms often overlapping, and that may evolve from what  
32 appears to be Parkinson's disease. The term "parkinsonism"  
33 shall include, but not be limited to, multiple system  
34 atrophy, dementia with Lewy bodies, corticobasal  
35 degeneration, and progressive supranuclear palsy;

36 (5) "Registry", the registry established by the  
37 medical university in section 191.1825.

191.1825. 1. Beginning January 1, 2024, the medical  
2 university shall establish a registry to collect data on the  
3 incidence of Parkinson's disease in Missouri and other  
4 epidemiological data as required in sections 191.1820 to  
5 191.1855. The database and system of collection and  
6 dissemination of information shall be under the direction of  
7 the medical university. The medical university may enter  
8 into contracts, grants, or other agreements as are necessary  
9 for the implementation of the registry.

10 2. The registry shall become functional and able to  
11 collect reporting data by August 28, 2024.

12 3. All patients diagnosed with Parkinson's disease or  
13 parkinsonism, as determined by the advice of the advisory  
14 committee, shall be notified in writing and orally about the

15 collection of information and patient data on Parkinson's  
16 disease and parkinsonism. If a patient does not wish to  
17 participate in the collection of data for purposes of  
18 research in the registry, the patient shall affirmatively  
19 opt out in writing after an opportunity to review relevant  
20 documents and ask questions. No patient shall be required  
21 to participate in the registry.

191.1830. 1. Within ninety days of August 28, 2023,  
2 the medical university shall establish the "Parkinson's  
3 Disease Registry Advisory Committee", which shall assist in  
4 the development and implementation of the registry,  
5 determine the data to be collected, and generally advise the  
6 medical university.

7 2. The committee shall be composed of at least the  
8 following members:

- 9 (1) A neurologist;
- 10 (2) A movement disorder specialist;
- 11 (3) A primary care provider;
- 12 (4) A physician informaticist;
- 13 (5) A patient living with Parkinson's disease;
- 14 (6) A public health professional;
- 15 (7) A population health researcher familiar with  
16 registries; and
- 17 (8) A Parkinson's disease researcher.

191.1835. 1. The medical university shall establish,  
2 with the advice of the advisory committee, a system for the  
3 collection and dissemination of information determining the  
4 incidence and prevalence of Parkinson's disease and  
5 parkinsonism.

6 2. (1) Parkinson's disease and parkinsonism shall be  
7 designated as diseases required to be reported to the  
8 registry. Beginning August 28, 2024, all cases of

9 Parkinson's disease and parkinsonism diagnosed or treated in  
10 this state shall be reported to the registry.

11 (2) Notwithstanding the provisions of subdivision (1)  
12 of this subsection to the contrary, the mere incidence of a  
13 patient with Parkinson's disease or parkinsonism shall be  
14 the sole required information for the registry for any  
15 patient who chooses not to participate as described in  
16 section 191.1825. No further data shall be reported to the  
17 registry for patients who choose not to participate.

18 3. The medical university may create, review, and  
19 revise a list of data points required to be collected as  
20 part of the mandated reporting of Parkinson's disease and  
21 parkinsonism under this section. Any such list shall  
22 include, but not be limited to, necessary triggering  
23 diagnostic conditions consistent with the latest  
24 International Statistical Classification of Diseases and  
25 Related Health Problems and resulting case data on issues  
26 including, but not limited to, diagnosis, treatment, and  
27 survival.

28 4. At least ninety days before reporting to the  
29 registry is required under this section, the medical  
30 university shall publish on its website a notice about the  
31 mandatory reporting of Parkinson's disease and parkinsonism  
32 and may also provide such notice to professional  
33 associations representing physicians, nurse practitioners,  
34 and hospitals.

35 5. Beginning August 28, 2024, any hospital, facility,  
36 physician, surgeon, physician assistant, or nurse  
37 practitioner diagnosing or responsible for providing primary  
38 treatment to patients with Parkinson's disease or patients  
39 with parkinsonism shall report each case of Parkinson's

40 disease and each case of parkinsonism to the registry in a  
41 format prescribed by the medical university.

42 6. The medical university shall be authorized to enter  
43 into data-sharing contracts with data-reporting entities and  
44 their associated electronic medical record system vendors to  
45 securely and confidentially receive information related to  
46 Parkinson's disease testing, diagnosis, and treatment.

47 7. The medical university may implement and administer  
48 this section through a bulletin or similar instruction to  
49 providers without the need for regulatory action.

191.1840. The medical university may enter into  
2 agreements to furnish data collected in the registry to  
3 other states' Parkinson's disease registries, federal  
4 Parkinson's disease control agencies, local health officers,  
5 or health researchers for the study of Parkinson's disease.  
6 Before confidential information is disclosed to those  
7 agencies, officers, researchers, or out-of-state registries,  
8 the requesting entity shall agree in writing to maintain the  
9 confidentiality of the information and, if a researcher,  
10 shall:

11 (1) Obtain approval of the researcher's institutional  
12 review board for the protection of human subjects  
13 established in accordance with 45 CFR 46; and

14 (2) Provide documentation to the medical university  
15 that demonstrates to the medical university's satisfaction  
16 that the researcher has established the procedures and  
17 ability to maintain the confidentiality of the information.

191.1845. 1. Except as otherwise provided in sections  
2 191.1820 to 191.1855, all information collected under  
3 sections 191.1820 to 191.1855 shall be confidential. For  
4 purposes of sections 191.1820 to 191.1855, this information  
5 shall be referred to as confidential information.

6           2. To ensure privacy, the medical university shall use  
7 a coding system for the registry that removes any  
8 identifying information about patients.

9           3. Notwithstanding any other provision of law to the  
10 contrary, a disclosure authorized under sections 191.1820 to  
11 191.1855 shall include only the information necessary for  
12 the stated purpose of the requested disclosure, shall be  
13 used for the approved purpose, and shall not be further  
14 disclosed.

15           4. Provided the security of confidential information  
16 has been documented, the furnishing of confidential  
17 information to the medical university or its authorized  
18 representatives in accordance with sections 191.1820 to  
19 191.1855 shall not expose any person, agency, or entity  
20 furnishing the confidential information to liability and  
21 shall not be considered a waiver of any privilege or a  
22 violation of a confidential relationship.

23           5. The medical university shall maintain an accurate  
24 record of all persons given access to confidential  
25 information. The record shall include the name of the  
26 person authorizing access; the name, title, address, and  
27 organizational affiliation of the person given access; dates  
28 of access; and the specific purpose for which the  
29 confidential information is to be used. The record of  
30 access shall be open to public inspection during normal  
31 operating hours of the medical university.

32           6. (1) Notwithstanding any other provision of law to  
33 the contrary, confidential information shall not be  
34 available for subpoena and shall not be disclosed,  
35 discoverable, or compelled to be produced in any civil,  
36 criminal, administrative, or other proceeding. Confidential  
37 information shall not be deemed admissible as evidence in

38 any civil, criminal, administrative, or other tribunal or  
39 court for any reason.

40 (2) The provisions of this subsection shall not be  
41 construed to prohibit the publication by the medical  
42 university of reports and statistical compilations that do  
43 not in any way identify individual cases or individual  
44 sources of information.

45 (3) Notwithstanding the restrictions in this  
46 subsection to the contrary, the individual to whom the  
47 information pertains shall have access to his or her own  
48 information.

191.1850. Sections 191.1820 to 191.1855 shall not  
2 preempt the authority of facilities or individuals providing  
3 diagnostic or treatment services to patients with  
4 Parkinson's disease or parkinsonism to maintain their own  
5 facility-based registries for Parkinson's disease or  
6 parkinsonism.

191.1855. 1. Before January 1, 2025, and before  
2 January first every year thereafter, the medical university  
3 shall provide a report to the general assembly that includes:

4 (1) A program summary update for that year on the  
5 incidence and prevalence of Parkinson's disease in the state  
6 by county;

7 (2) The number of records that have been included and  
8 reported to the registry; and

9 (3) Demographic information, such as a breakdown of  
10 patients by age, gender, and race.

11 2. The medical university shall also publish the  
12 annual report required under this section in a downloadable  
13 format on its website or on the registry's webpage.

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